Ensuring High-Value Care for People with Serious Illness

Millions of Americans Living with Serious Illness Have Unmet Needs
11.8 million adults in the United States are living with at least one serious illness, and this number is expected to increase significantly over the next two decades. Serious illness is a health condition that carries a high risk of mortality AND either negatively affects a person’s daily functioning or quality of life, or excessively strains caregivers. Examples of serious illnesses include metastatic cancer, advanced dementia, and frailty. Despite high health care utilization and spending among those with serious illness, this population (which also includes upwards of 400,000 children) receives care that is characterized by inadequately treated symptoms, poor communication with health care providers, and enormous strain on family members or other caregivers. Improving care for the seriously ill and their families requires a health system that routinely elicits their values and goals, aligns treatment decisions with those goals, assesses and addresses symptom burden, and – in the most complex cases – facilitates access to consultation from board-certified palliative care specialists.

Current Gaps in U.S. Health Care
The U.S. health care system, built on treating acute illness and injuries, has significant gaps in caring for patients with serious illness and their families. These include:

- Insufficient data and systems to proactively identify the seriously ill, largely due to the lack of functional and cognitive status data collection across care settings
- Insufficient access to meaningful and timely response to crises on a 24/7 basis
- Insufficient knowledge and skill among treating clinicians for safe and effective pain and symptom management, and for the communication skills necessary to hold difficult conversations with patients and families about their priorities for care in the context of their illness
- Clinician inability to take quality of life into consideration when offering treatment recommendations
- Inconsistent access to certified palliative care specialists and programs that adhere to national quality guidelines, due to workforce, payment, and regulatory barriers

These gaps often result in avoidable spending as people seek emergency care for preventable problems or undergo unnecessary procedures that they may not have chosen if they had had a full understanding of the benefits and risks. Only 5 percent of the US population — many of whom have long term and serious illness — drive over 50 percent of total health care expenditures, and yet much of this spending is both unnecessary and preventable.
Driving Towards Standardized High Value Care for Seriously Ill Patients

Numerous studies show that palliative care significantly improves patient and family caregiver quality of life and lowers symptom burden. This results in fewer symptom crises, 911 calls, emergency department visits, and hospitalizations. This is a triple win – better outcomes for patients and their families, clinicians, and payers of health care. Yet, reliable access to clinicians who can deliver quality palliative care is highly variable and only slowly increasing. To achieve the system-wide changes required to improve care for this population, policymakers must consider modifying existing requirements and/or incentive systems to promote adherence to national guidelines for access to high quality palliative care. For example:

- In 2014, California passed a law that required the state’s Department of Health Care Services to establish benefit standards for access to palliative care services for all patients served by Medicaid managed care plans.
- In 2014, Wells Fargo required its health insurance plan to develop benefits and services for seriously ill participants, in accordance with the National Consensus Project (NCP) Clinical Guidelines for Quality Palliative Care for comprehensive palliative care.
- In 2017, Anthem’s health plan bonus incentives for network hospitals included access to quality hospital-based palliative care, along with training and commitment of resources as a criterion for contract payment increases. To earn credit for this measure, network hospitals can either achieve Advanced Certification for Palliative Care from The Joint Commission or demonstrate similar policies and capabilities.
- In 2017, California passed a law allowing licensed hospices to provide palliative care services concurrently with curative treatment to a person who does not have a terminal prognosis or who has not elected to receive hospice services.

Recommendations for State Policymakers

States leaders can play an important role in improving care for people with serious illness through legislation and/or regulation. Activities might include:

- Inserting a definition of and minimum standards for palliative care in the state code
- Revising state health professional licensure and/or continuing education requirements to include a minimum number of hours in the basic components of palliative care, i.e., communication and pain and symptom management
- Requiring standardized policies and procedures around palliative care in hospitals, nursing homes, and the home as a condition of licensure or condition for participation in the State Medicaid program
• Revising health plan network adequacy requirements to specify access to board-certified palliative care clinicians, as well as access to hospitals, nursing homes, and home health agencies that demonstrate standardized processes for communication and pain and symptom management.

• Requiring Medicaid managed care plans to cover, for specific beneficiaries, home-based palliative care services that adhere to the NCP Guidelines.

• Requiring Medicaid providers and managed care plans to systematically collect functional and cognitive status data to support proactive identification of high-need, high-risk patients.

• Establishing separate licensure for home-based palliative care and/or modifying existing licensure (e.g., for hospice or home health) to oversee care delivered in the home.

• Expanding public reporting of health plan quality measures to include relevant measures, such as number of days at home in the last 90 days of life.

The Center to Advance Palliative Care (CAPC) has information and resources to help promote high quality palliative care. For more information, please contact Stacie Sinclair, Senior Policy Manager, at stacie.sinclair@mssm.edu.

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1 The Commonwealth Fund “High-Need, High-Cost Patients: Who Are They and How Do They Use Health Care?” August 2016


16 Meier DE. Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care. The Milbank Quarterly September 2011; 89(3):343-380.


19 Palliative care is defined as specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.


It is up to states to review and implement these recommendations based on feasibility within their local environment.

Example definitions from Colorado (http://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-1%20Chap%202002) and Maryland (https://health.maryland.gov/ohcq/Documents/Palliative%20Care_10.07.01.31.5_18_2016.pdf) can provide a helpful starting point.

This can be demonstrated by meeting updated state survey requirements that include palliative care or by obtaining programmatic certification in palliative care. The Joint Commission offers Advanced Certification in Palliative Care for hospital inpatient programs (https://www.jointcommission.org/certification/palliative_care.aspx) and Community-based Palliative Care Certification for home health and hospice (https://www.jointcommission.org/community-based_palliative_care_certification_option_july_1_2016/). DNV GL Healthcare offers Palliative Care Program Certification for hospital inpatient palliative care programs (https://www.dnvgl.us/assurance/healthcare/PalliativeCare.html).

Again, this can be demonstrated through performance on state surveys, or program certification from organizations such as TJC and DNV GL.

These requirements can be modeled after recent guidance from the Centers for Medicare and Medicaid Services (CMS) which: 1) allows Medicare Advantage (MA) plans to cover supplemental benefits and cites home-based palliative care as an allowable benefit; and 2) provides new flexibility for plans to vary benefits for subsets of enrollees based upon their disease state or health status, as long as these variations are available to all similarly-situated enrollees. Guidance retrieved from https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/HPMS/HPMS-Memos-Archive-Weekly-Items/SysHPMSMemo-2018-Week4-Apr-23-27.html

Data collection can include items from the IMPACT Act, which requires certain post-acute care facilities to submit data on quality measures around function status, and cognitive function and mental status, among other things. More information can be found at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/IMPACT-Act-of-2014/IMPACT-Act-of-2014-Data-Standardization-and-Cross-Setting-Measures.html

Additional measures could include: proportion of patients who died from cancer receiving chemotherapy in the last 14 days of life (NQF #0210); proportion with more than one hospitalization in the last 30 days of life (NQF #0212); number of burdensome transitions in last week of life; hospice utilization (as a percentage); and hospice length of stay (in days).